The Share4Rare hackathon sets the foundation of solving the rare disease isolation using chatbots

- The Universitat Politècnica de Catalunya has organized RareHacks, the first hackathon on rare diseases within the framework of the Share4Rare project of which it is a member.
- The objective of this event was to build a chatbot to respond to the need of patients and families affected by rare diseases to access quality and curated information.
- Fundació per la Recerca Sant Joan de Déu Research Foundation – Sant Joan de Déu Children's Hospital Barcelona leads this European project that aims to connect and empower families affected by rare diseases through an online platform and collect data to advance research.

Barcelona – July 10, 2019. Share4Rare's first **RareHacks** hackathon was held this weekend in Barcelona. In total, **45 participants** were involved in the challenge to build an innovative chatbot to solve the rare disease challenge based on the limited access to reliable medical information. Specifically, the exercise was focused in the **paediatric melanoma** that is a very ultra-rare condition due to the low prevalence of the disease and its cause that differs from the adult melanoma.

In total, 6 teams completed the process which was held at **MOB Barcelona**, a creative hub in the heart of Barcelona. The 6 teams coded, pitched and demoed their chatbot to five judges: **Samir Kanaan** from Universitat Politècnica de Catalunya, **Begonya Nafria** from Fundació Sant Joan de Déu, **Xavier Escoté** and **Salvador Cuadras** from Deister software, and **Alexandre Perera** from Universitat Politècnica de Catalunya.

The winning team was awarded to **Sergi del Río**, **Celia Sanchez**, **Lucía Chacón**, **David Pujol** and **Oriol Aranda**, who built the **RareBot**: a chatbot that provides information accordingly with the different types of melanoma and helps the users with the details about the nearest certified centre (hospital) according to their **geolocation**. The team added translation capabilities so the user can interact with the bot in **any language**, although the system is trained with texts in English. Other additional features of their proposal are the correction of the misspelling during the interaction, inclusion of different questions for the previous validation of the right type of melanoma in order to show the reliable information, and concurrent multiple users.

The second place was awarded to **Pau Cutrina**, **Marc Sos**, **David Sanchez**, **Josep Cordón**, **Edgar Alarcón** and **Josep Munuera** who used a dynamic called *web scraping*. With this design there will be no need to have a doctor to label the database since they use the already existing labelled database. They planned a scalable solution that updates by itself and flexible to other diseases.

The event was organised by UPC (University of Politecnica Catalunya), one of Share4Rare's consortium partners. Participants started Friday morning fresh after receiving a series of motivating and tech talks aimed to gain a deeper understanding of the disease and to solve the challenge. Dani Tost, from UPC kicked the hackathon off with a welcome talk about biomedical engineering.

Begonya Nafria introduced the aim of Share4Rare, a digital platform based in the collective intelligence of patients and families living with rare diseases in order to increase the research in this field. Additionally, other presentations offered to the participants of RareHacks instructions and the patients' perspective from Melanoma Patient Network Europe's chair **Bettina Ryll**.

Friday afternoon was for team building and idea pitching. Then, all teams worked until late to set up structures, scrap information, and build on the foundations of their own chatbot, iterating and pivoting throughout the process. Although all teams used Python for their chatbot, several teams changed their plans at least once during the days.

All teams received feedback and guidance along the event. The seasoned experts included Alex Perera, Samir Kanaan and Jordi Fonollosa from UPC.

Antonella Romanini, oncologist at the Azienda Ospedaliero-Universitaria Pisana, who joined the hackathon to provide clinical background information on the condition, commented: "*What amazes me is that they are all so incredibly bright. I was telling many things and they picked out just the right things to start coding*". **Alex Perera** continues: "*It's awesome to see how everybody treats another with respect and to work towards a common goal even though they never met before*".

The winning team **was awarded € 1.500 euro**; sponsored by Deister Software. All insights from this hackathon will be analyzed in order to be incorporated in a future iteration of the **Share4Rare** platform in order to improve the user experience of the tools related to the access of curated and validated information about rare diseases.

Inquiries about this event, or the Share4Rare project, can be directed to Suzie-Ann Bakker at info@share4rare.org.